Whisper Your Way Into Their World:
A Loving and Gentle Approach to Those with Alzheimer’s Disease

By Lisa Yarkony
“Many times, families make a promise. But they don’t know the cost of that promise,” Dr. Verna Benner Carson told attendees of the 5th Annual Private Duty Home Care Leadership Summit & Exposition. “They tell their mom, their dad, ‘I’m never going to place you in an institution.’ Then, sometimes during bathing, the daughter gets spit on or hit, and she thinks, ‘I didn’t sign on for this. I made a promise, but I didn’t think it would include hitting me’” — an all too common thought among families and caregivers of patients with Alzheimer’s disease, who can exhibit aggressive or other difficult behaviors. But there are ways to reduce this aggressive behavior, or take what can be frustrating behaviors and turn them more positive, according to Carson, who has taught her insights to 2,000 practitioners in the field of senior care.

Carson is the former national director of Tender Loving Care Health Care Services, a former associate professor of psychiatric nursing at the University of Maryland, current president of C & B Senior Care Specialists, and a national expert on mental health nursing. She’s also the creator of the “Alzheimer’s Whisperer” program, which teaches caregivers how to enter the unique world of Alzheimer’s patients so they can calm the broken spirits of those who suffer the degenerative effects of this cruel disease.

The innovative program is also a boon to families of loved ones with Alzheimer’s, and Carson says she wishes she could reach them all. “If I could take the program across the country, I’d speak at street corners to teach people,” she told attendees of the NAHC- and PDHCA-sponsored conference, “because Alzheimer’s is a terrible disease and families are struggling to manage it. They’re stressed, and when you’re stressed, you can’t think creatively.” She contended, however, that some of the techniques of the Alzheimer’s Whisperer program “are so easy and accessible to both families and professional caregivers,” many of whom have seen the impact of Alzheimer’s on their own parents, too.

So Carson struck a chord when she asked, “How many of you in this room have a loved one with Alzheimer’s disease? How many of you have a patient who has Alzheimer’s or a diagnosis of dementia?” The many hands that went up in the room led her to note, “The business opportunity in this area is huge. If you had a special program that would allow your caregivers to be skilled in this area, not only would the families love you and want your services for a long time, you’d also be making a profound difference in those families’ lives.” And yes, there are steps to doing it, Carson went on to explain.

“What does it mean to become an ‘Alzheimer’s whisperer?’” she mused. Carson explained that it requires a perspective shift and some letting go of rigid ideas — and moreover, this doesn’t have to be a chore or a hardship. “It’s an approach that’s gentle and flexible and can be very fun,” she said. “When you give up the idea that you’ve got to bring that person [with Alzheimer’s] into your reality and you can go in their reality and let your imagination go, it’s fun. It allows you to be creative, and it allows you to think outside the box. An Alzheimer’s whisperer is a person who can enter the world of that person and understand that world.”

This sense of empathy is the key to dealing with Alzheimer’s patients, because nine out of 10 problems with these patients that must be confronted by caregivers, paid or unpaid, “are caused by the caregiver,” Carson asserted. “Think about it,” she said. “It’s the way we talk to a person, the demands we make, and the way we approach activities like taking a bath...
— ways that often generate a negative reaction from the person who has the disease. We have to be able to understand their world and change our expectations of what that person is able to do.”

Caregivers also must perform a bit of a balancing act, Carson said. “If you live with someone who has Alzheimer’s, you see the behaviors of a toddler as they move into the middle stage of the disease. This doesn’t mean you treat them like a toddler. We don’t talk to them like they’re babies because they still have a feeling of being adults,” she told attendees. “But their ability to make decisions is at a much lower level, and that opens up a whole series of interventions you don’t have when you’re thinking this person is 85 years old. You might say to yourself, ‘They should know better than that.’ And they did, before they were cognitively impaired. So we have to change our own behavior as the disease progresses.” It’s easier to do this, according to Carson, if one understands what’s happening to those suffering from Alzheimer’s on a physical level.

“The behaviors of an Alzheimer’s patient are tied to changes in the brain,” Carson said as she chauffeured listeners on a quick trip through the workings of the human brain. “The first area to change is the hippocampus, the part of the brain that processes experiences and stores short-term memories, while the last area is the frontal lobe, which stores long-term memories,” Carson noted. As a result, she pointed out, earlier-stage Alzheimer’s patients will “hold onto their old stories but don’t remember what they had for breakfast.” Once a patient gets to the middle stage of the disease, he or she will have only about five minutes of short-term memory, Carson said, “and you can’t start a conversation with five minutes of short-term memory; you can’t make small talk. So if you expect mom or dad to converse with you about what’s going on, realize it’s not going to happen.”

That dearth of short-term memory and resulting problems with social skills aren’t the only unnerving changes that Alzheimer’s patients will go through, Carson said. “There’s damage to the parietal lobe, the part that controls spatial orientation, so people get lost. The limbic system, or the emotional control center, gets damaged. The hypothalamus, which regulates appetite, also gets damaged, and in the last days, it shuts down so people don’t want to eat, just one of the many odd behaviors we see that are controlled by different parts of the aging brain.” So with erosions and breakdowns of social skills, short-term memory, one’s sense of spatial orientation, emotional control, and appetite, the takeaway is to know that this will happen, according to Carson. “Understanding this makes it easier to accept the behaviors because the person isn’t deliberately doing something to aggravate you,” she noted.

All these behaviors are explained by the theory of retrogenesis, the idea that the aging brain devolves in the opposite direction from that in which it developed. “In other words,” as Carson phrased it, “once an adult and twice a child; we go back to our childhoods.” She gave an example of an infant being unable to hold up its head, which she noted is the last ability to be lost. “You also know, if you’ve taken care of someone at the end, that they’re curled up in the fetal position like a baby,” Carson maintained. Similarly, Alzheimer’s patients often become incontinent, “a horrible issue for families,” she observed, “and if we could teach them how to cut down on ‘accidents,’ it would be a huge gift.”

Some families just won’t listen to advice, according to Carson, who told attendees of a family whose elderly parents both had Alzheimer’s, which was causing them to exhibit some dangerous symptoms and behaviors. “The father was in the early stages. The mother was in the middle stages and had already set three fires while cooking. The daughter was in denial, but the neighbors were terrified, so we were called in,” she said. “We pulled together a report for adult protective services because we could not get the daughter to move. A nurse came to visit, and the mother greeted her. She had
on a beautiful skirt and sweater. On top of that, she had her bra and panties. The daughter said, ‘What do you expect? My mother’s in her eighties.’ And I said, ‘I don’t know about you, but I know a lot of eighty-year-olds who dress appropriately.’”

And this elderly mother would have dressing appropriately, too, were she aided in getting dressed similar to the way a child would be, Carson contended. “She didn’t need someone to dress her,” she quipped, “but she did need the appropriate cues and for someone to tell her the order. When you face a situation like this, think forward progression of the child and backward progression of someone who has the disease.” How, then, should the caregiver shape his or her interventions with the patient?

Think again in terms of a young child, Carson proposed, when dealing with things like repetition — another behavior that can be very frustrating for caregivers of those suffering from Alzheimer’s — and find a way to turn that behavior into a more positive reinforcement. “Repetitive, productive activities can help,” said Carson, “because people with Alzheimer’s can only do one thing at a time. You can take that repetitive behavior and use it as a skill.” Women, for example, might engage in work like sweeping floors or folding linens, and they can do it several times in a row, Carson explained. “Say mom is folding towels into a basket, so she’s occupied and not asking repetitive questions. The daughter has some work to do so she takes the basket away, messes it up, and comes back five minutes later. She can ask the mom to fold the towels all over again, and she’ll happily do it because she doesn’t remember doing it before.”

This same technique can be used on men, Carson maintained, although caregivers will need to find something for them to do besides sweeping floors and folding laundry. “Most men of this generation are not going to sweep floors and fold towels,” she pointed out. “But one tremendous activity for men is Legos — they’ll spend hours matching colors and building things. Or how about if you knew someone was a carpenter and you gave him wood and nails? He might work for hours getting those nails into the wood. There’s always something there; it’s our job to reach it and find a way to deal with challenging behaviors. A lot of it has to do with our approach,” Carson said. This is especially true when it comes to everyday activities like dressing and bathing, she added.

“Most elderly people who are bathed by someone else are showered,” Carson acknowledged. “A shower to a three-year-old is a terrifying experience, with all that water coming down. We shower people who are at a three-year-old level, and some are not okay with it. But instead of forcing them to do something that terrifies them, we can give them alternatives like sponges, she suggested. “Or we can bathe them in bed or in a chair. One nurse used to get a patient into the shower by singing Happy Birthday.”

A shower shouldn’t be a special event, per se, but elderly patients often don’t need to bathe every day anyway. “Elderly people don’t need to bathe as often,” Carson said, “because their skin gets dry. We need to change our expectations and our approach to bathing.” The same goes for agitation and aggression among Alzheimer’s patients, which are important issues considering how many caregivers refuse to go back to a job after getting kicked, bitten, or otherwise physically abused. “There can be multiple reasons why people with Alzheimer’s kick, hit, or bite,” Carson noted. “But the number one issue is pain — unrecognized and untreated pain. When patients are in the middle stage, at the level of a three-year-old, to say they ‘hurt’ is an abstract thing; they can’t do that anymore. And the number one cause of pain is arthritis. So let’s say mom is in pain, and she can’t tell you; she tries to slap you if you move her in a quick or rough manner because that makes her joints hurt even more.”

The answer is not just to ignore the patient’s distress, Carson advised, citing a study done in a skilled nursing facility where patients exhibited frequent agitation. “Patients kept calling out, ‘Help me. Help me. Take me home!’ When the staff asked the patients if they were in pain, they said no. The staff didn’t know what to do, so after a while they did nothing. One nurse with some expertise in pain management said...
to a doctor, “This frightens me. When we stop responding to these cries of pain or need, we get hardened to other things as well — it’s easier not to respond to other things as well. So can we do a little research? Let’s divide the facility into two, give Tylenol every four hours to half the patients, and do the same as we’ve been doing to the other half.” The facility tried this approach for a week, and vocal outbursts and agitation ceased among patients who were given Tylenol, Carson related.

The change in behavior, Carson said, underscores the need to manage pain better for those with Alzheimer’s. “That to me is the most important thing to know,” she maintained, “because if people are not getting hit, they can tolerate more of the other behaviors of Alzheimer’s patients. I bet you’ve all gotten a phone call from one of your direct care providers and heard them say, ‘I just got hit. Take me off this case. I’m not coming to see this patient one more time.’ [Caregivers] need strategies to deal with this behavior, and so you can give them these strategies,” she continued.

Wandering, for instance, can be another dangerous and problematic behavior in Alzheimer’s patients, but even that can seen as a good thing if kept under control “because it keeps their legs strong and they’re still walking,” Carson said. “But it can lead to problems, so the Alzheimer’s Association runs a ‘safe return’ program,” she noted. “It costs $50, but they have scholarship programs for people in need. You register the person; you get a medical alert bracelet; and your loved one’s vital statistics get entered into a national database,” Carson said. Then, if and when that patient goes missing, a search can be initiated, she explained.

Meanwhile, caregivers can help avoid this “gone missing” scenario by taking simple steps to prevent wandering in the first place. “If you’ve got the person at home,” Carson advised, “you’ll want to have a deadbolt lock at either the top or the bottom of any exterior door. People with Alzheimer’s tend to have vision issues in this area, and they don’t see well at the top and the bottom. Many of them also lose their depth perception, and this suggests another technique to prevent wandering: Put a black rug taped down in front of every exit door. To people without depth perception, a black rug looks like a hole. They won’t go over it because they’re afraid they’ll fall in.”

People with Alzheimer’s see the world differently with their eyes, Carson told listeners. They also perceive it differently with their minds, so the way caregivers communicate with these patients makes a difference. For example, “don’t

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quiz the person because that upsets them,” Carson stressed. “Don’t argue or reason. In fact, if I had to rewrite the Ten Commandments for the Alzheimer’s patient, number 11 would be ‘Thou shalt not argue,’ and number 12 would be ‘Thou shalt not reason,’” she said. “Nobody wins an argument with someone with Alzheimer’s, so don’t try to correct their reasoning. You’ll only be frustrated,” Carson maintained, noting she had realized this early on in her career as a nurse.

“I was seeing patients,” she recalled, “and a woman asked me what I had had for breakfast. So I told her. She said, ‘Isn’t that funny, we had the exact same thing.’ Of course, we didn’t have the exact same thing, but she didn’t remember what she ate. I remembered what I ate, so I’d supplied her with the answer. You have to work with [Alzheimer’s patients] for a while to realize that they’re not always telling you the truth — but they’re not lying to you, either.” Besides, sometimes the truth does hurt, a lesson that was lost on a facility with a problem patient named Lucy, Carson said to the audience.

“Every night,” Carson detailed, “Lucy would get up and look for her dead husband. Afterward, she would crouch in the corner while the staff said, ‘Lucy, he’s dead; stop looking for him.’ And she’d agree, because what kind of wife was she if she didn’t know her husband was dead?” However, the patient continued to search for her dead husband, until the facility staff were ready to send her to a psychiatric hospital.

“So my colleague, Katherine, came in and said, ‘Can I have 10 minutes with her?’” Carson said. “Katherine asked Lucy what was wrong, and Lucy said, ‘I’m looking for my husband.’” Katherine suggested they go to Lucy’s room, where they played cards and talked until Lucy fell asleep. “When Katherine came out,” Carson related, “she told the staff, ‘You don’t want to confront her with that truth anymore. This is a very harsh thing to do when she has no memory of that.’”

Caregivers should take the same approach with other Alzheimer’s patients, Carson urged listeners. “Sometimes the truth is very painful, and the person can’t handle it,” she said. “The truth can hurt so much that it’s not worth going there. Instead, be willing to enter into that person’s world. It’s so much fun to be part of their stories instead of correcting them.” One nurse, Carson recalled, had recognized this after hearing her presentation on the Alzheimer’s Whisperer program.

“I made a presentation to 50 people,” Carson said to attendees. “The next day, I got an email from one of the participants. She told me her name was Melva Gay, and her mom had always called her Melva. She’d decided ‘Melva’ wasn’t a professional name; when she got to be an adult, she wanted everyone to call her Gay,” she said. “But this didn’t ring a bell with her mother, who’s in a facility with Alzheimer’s and hadn’t spoken to her daughter in six months. So after the presentation, Gay went to visit her and said, ‘Mom, this is Melva.’ Her mom broke into a big smile and said, ‘Melva, I love you so much. Where have you been?’ She’d been there all along, but her mom didn’t relate to the name “Gay.” She called her Melva. When Melva came back into her life again, what a gift that was! And it was all because she was willing to go back in time to what her mother was familiar with.”

This is the heart of what it means to be an Alzheimer’s whisperer. “It’s a technique that’s so easily learned,” Carson told the crowd. “It benefits you as a caregiver. It benefits your staff who are caregivers, and it benefits all those families who are going to be using the services you provide.” Caregivers can make a big difference by learning to whisper their way into the worlds of those with Alzheimer’s; it’s a loving, gentle approach that can help families keep the promises they make to mom and dad.

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